

The Carers' Alert Thermometer (CAT): supporting family carers of people living with motor neurone disease

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ABSTRACT

Background: Burden and distress among family carers of people living with motor neurone disease (MND) are reported widely. Evidence-based screening tools to help identify these carers' needs and plan appropriate support are urgently needed. **Aim:** To pilot the Carers' Alert Thermometer (CAT), a triage tool developed to identify carers' needs, with family carers of people living with MND to determine its usefulness in identifying their need for support. **Methods:** Training workshops with MND Association visitors (AVs) and staff in southwest and northwest England, followed by implementation of the CAT. A self-completed online survey and semi-structured telephone interview evaluated use of the CAT. **Findings:** Sixteen participants completed the online survey with 11 volunteering to be interviewed. The CAT has potential to map change over time, help to focus on carers' needs and improve communication with carers. **Conclusion:** The CAT provides a structure enabling AVs to engage in a meaningful process with family carers to identify and discuss their needs.

Key Words family carers; carer needs; MND; evaluation; volunteers; pilot study

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disease, people living with MND will ultimately require assistance with many activities of daily living, including washing, dressing, eating and drinking, mobilisation and communication, as well as aspects of medical care (Chiò et al, 2006). It is known that multidisciplinary team (MDT) involvement is beneficial for people living with MND and their level of satisfaction with care (Miller et al, 2009; O'Brien et al, 2011); however, most people living with MND are cared for in their own homes by family members until death (Rabkin et al, 2000; Mockford et al, 2006). Caregiving duties occupy, on average, 11–15 hours a day (Krivickas et al, 1997; Chiò et al, 2006).

Caring for a family member with MND is known to be a source of burden (Goldstein et al, 2006; O'Brien et al, 2012; Creemers et al, 2016), depression (Gauthier et al, 2007), anxiety (Rabkin et al, 2000) and emotional distress (Kaub-Wittemer et al, 2003). Furthermore, providing care can have a negative effect on carers' quality of life (QoL) (Peters et al, 2013; Galvin et al, 2018), with some carers reporting their QoL to be lower than the people with MND for whom they care (Kaub-Wittemer et al, 2003). Family carers' QoL, feelings of depression and psychological wellbeing have been identified as negatively influenced by advancing care demands as the disease symptomatology progresses (Creemers et al, 2016). Research has shown that cognitive and behavioural changes are frequently apparent in MND (Goldstein and Abrahams, 2013), which also substantially increases family carers' burden (Lillo et al, 2012).

There is a growing body of literature exploring family carers of people living with MND and the associated physical, emotional, social, financial and psychological ramifications (Sorrell, 2014). There is also evidence to support the relationship between specific patient factors (behavioural impairments, physical functioning) or carer factors (feelings of depression) and carer burden (de Wit et al, 2018a). Furthermore, family carers rarely discuss their own needs or consider seeking help for themselves, deferring instead to the needs of the person for whom they care (Aoun et al, 2012; Galvin et al, 2018; de Wit et al, 2018b). It is clear that caregiving exerts both a physical and emotional toll on individuals,

Motor neurone disease (MND) is a neurodegenerative condition, comprising four main sub-types, which results in voluntary muscle weakness, leading to loss of limb function and difficulties with speech, swallowing and respiration (O'Brien and Claburn, 2016). It is a terminal illness, and six new people are diagnosed with the disease every day in the UK, which results in around 5000 people being affected by MND at any one time (MND Association, 2018). One-third of these people will die within a year, and more than half within 2 years of diagnosis. Due to the progressive nature of the

with the potential to result in significant cost to society if carers' needs are not identified and met (Hollowood, 2018). Interventions to improve the carer experience in MND are lacking (Aoun et al, 2013) and there is a sparsity of evidence-based instruments suitable for use in everyday practice to assess the needs of family carers who provide end-of-life care for people who remain living at home (Hudson et al, 2010).

Using a mixed-method consensus approach, the Carers' Alert Thermometer (CAT) was developed to fill this gap (Knighting et al, 2015; 2016). The CAT (*Figure 1*) was designed as a speedy alert tool to be completed by non-specialist staff or volunteers, collaboratively with the carer, to help identify and triage the needs of carers of family members or friends with advanced or progressive illness; it does not replace a full assessment, but can identify the need for such an assessment at an early stage. Ten alert questions are set out under two themes: support needed by the carer to provide care; and support needed for the carer's own health and wellbeing. A traffic light system signifies the level of need for each alert question, while a visual thermometer indicates the degree of the carer's needs. A guidance section of next steps applicable to each alert can be customised locally and space is provided to create an action plan and future review dates (Knighting et al, 2016).

While the burden associated with caring for a family member with MND is well known, what is less clear is what might be done, on a practical level, to identify the issues affecting individual carers so that tailored support can be put in place to ameliorate their situation and enable them to continue to provide care. It is known that formal assessment of family carers by care staff provides reassurance and validates their care role, while allowing staff to provide more structured follow-up focusing on the carer and family (Aoun et al, 2017). However, care staff are overstretched and have to prioritise the needs of patients over those of carers. An alternative is for volunteers to work with carers to help identify and triage their needs using an alert tool such as the CAT, but no previous work has explored the use of volunteers working in this way with carers of people living with MND. MND Association visitors (AVs) are volunteers who receive training to help support people living with MND and their families. We therefore set out to pilot the use of the CAT by AVs with family carers of people living with MND to determine its usefulness in identifying their need for support.

Method

The pilot study comprised two distinct stages: training and implementation; followed by data collection for evaluation.

Stage 1. Training and implementation

Workshops were held by the research team in 2015 and 2016 for AVs and staff in northwest and southwest

England. The purpose of the workshops was to review the CAT, demonstrate resources, including an instructional DVD, and train attendees on how to use the tool through role play. Feedback gained from participants during the workshops endorsed modifications to the CAT wording and format to promote usability for non-healthcare staff (e.g. removing some patient information and replacing the term 'risk' with 'need'). In the months following the workshops, participants piloted use of the CAT with family carers of people living with MND during routine appointments.

Stage 2. Data collection

Whether they had used the CAT or not, attendees of the workshops were invited to provide feedback through an online survey. As outlined in *Table 1*, the survey included six demographic questions, eight questions for people who had not yet used the CAT and 12 questions for people who had experience of using the CAT with carers. Open questions were included to explore idiographic experiences of using the CAT, and also to identify any potential changes which may improve its use in practice.

Participants who completed the survey were also invited to take part in a semi-structured telephone interview to provide additional detail of using the CAT with MND carers. To gain supplementary data from a strategic perspective, senior members of the MND Association, who were involved in the workshops, in the form of managers and regional care development advisors (RCDAs), were also approached to participate in an interview. All interviews were digitally recorded and professionally transcribed, with information which might identify participants being omitted before allocation of ID codes to ensure anonymity. Data were collected between February 2016 and October 2018.

Ethical considerations

Workshop attendees were sent a link to the online survey to complete a minimum of 3 months after they attended the workshop. The first part of the survey comprised a participant information sheet to explain what was required of participants and what would happen to the data. Responses to the survey were anonymous and consent was assumed on submission of the survey. Volunteers were sought for interview, but contact details were submitted separately to the survey, to maintain anonymity of survey responses. Prior to interview, potential participants were sent a participant information sheet and consent form. As all interviews were by telephone, verbal consent was obtained and audio recorded by the researcher reading through the consent form and obtaining a positive response from the participant to indicate their willingness to proceed. The study, in which the MND Association participated, was granted approval to proceed from an Edge Hill University research ethics committee (Reference: LTC 53).



Carers' Alert Thermometer (CAT) v2.1

mnda
motor neurone disease
association

Edge Hill
University

INSTRUCTIONS

Section 1 and 2 to be completed together, ticking the level of need for any alerts which could impact on (a) the care being provided or (b) the carer's own well-being;



NO or LOW need



INTERMEDIATE need



HIGH need

Section 3 circle the total number of intermediate (amber) and high needs (red) alerts on the thermometer;

Section 4 make a plan with the carer; prioritising the top four alerts for action and noting the agreed next steps for the priority alerts identified;

Section 5 set a review date and person responsible for follow up. All questions to be revisited during a review to monitor the support provided and any change in the alerts. It is recommended that monitoring and review dates be more frequent for carers with alerts which are considered 'HIGH' (red) or 'INTERMEDIATE' (amber).

SECTION 1: PLEASE COMPLETE THE DETAILS BELOW

Date CAT conducted:..... By (Staff name):..... Tel:.....

Carer's Name: Name of person caring for:.....

Relationship to person caring for: (circle) Spouse / Parent / Child / Sibling / Friend / Other:.....

Carer's Address:.....

Carer's telephone number(s):.....

Is the carer's address different to the person being cared for? Yes No

SECTION 2: IDENTIFY & ASSESS THE NEEDS OF THE CARER

This section contains questions to identify areas of need that carers may experience. Please go through each question together circling the level of need identified, even if no needs or concerns are identified at Q1.

[x] = person being cared for e.g. husband or wife.

A. CURRENT CARING SITUATION

Q1. Do you currently have any needs or concerns about caring for your [x] or your own health and well-being? (please circle one) Yes No Unsure

Q2. Do you need any information about the condition your [x] has and how the care needed might change over time?



Q3. Do you need any help to provide any of the physical or general daily care your [x] requires?



Q4. Do you need any help to provide any emotional or spiritual care your [x] requires?



Q5. Do you have a named person to call in an emergency or out-of-hours to discuss any concerns about your [x]?



B. CARER'S HEALTH AND WELL-BEING

Q6. Do you feel involved in discussions and listened to by professionals about the care needed by [x]?



Q7. Do you need any help or information about money or legal issues?



Q8. Do you need a break from caring during the day or overnight?



Q9. Do you need any help to balance your own needs with the demands of caring? (e.g. attend own health appointments, social activities)



If appropriate include:

Q10. Do you know your [x]'s wishes and preferences for EoL care? (If known, have they been written down and shared, e.g. advance care planning (ACP) doc?)

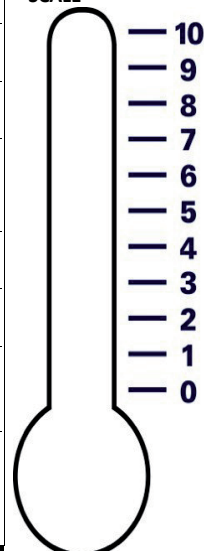


Sub-total of amber and red alerts

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SECTION 3.

CIRCLE THE TOTAL NUMBER OF AMBER AND RED ALERTS ON THE THERMOMETER SCALE



CAT_ Version 2 © Edge Hill University Any correspondence to eprc@edgehill.ac.uk Further information is available at www.edgehill.ac.uk/carers

Figure 1. Carers' Alert Thermometer (CAT)

Carer's Name:..... Date completed:.....Page 2 of 2

SUGGESTED NEXT STEPS Some general guidance is included below which can be amended by managers or senior clinicians of the service to help guide staff responses when conducting the CAT based on available local services and support.

Q1	If no needs raised with this opening question continue with the rest of the CAT. If there are needs raised, listen to them now before progressing with the CAT, as it will help to guide you about the carer's priorities.
Q2	Provide information to the carer if appropriate or refer to the appropriate professional.
Q3	Identify area of need, and provide information or onward referral as appropriate.
Q4	Discuss local & national sources of support for the carer & advise on routes of support for the patient e.g. GP, counselling services, hospice team.
Q5	If not, ensure carer knows about the GP out-of-hours service or similar (eg. Local hospice helpline).
Q6	Discuss carer's concerns; if appropriate, liaise with appropriate health & social care professionals.
Q7	Provide information on local services e.g. local carer centre/ Citizen's Advice Bureau.
Q8	Provide information about local authority carer assessments, local respite care or sitting services if available.
Q9	Provide information about local services and support e.g. support group meetings, carer centre.
Q10	If appropriate, ask if they would like information on Advance Care Planning.

SECTION 4: PLAN. Use this table to briefly note the details of up to four priority alerts requiring action now, any actions taken today, and any next steps which have been agreed with the carer.

Brief summary of needs identified by alerts (If there are several needs, ask the carer to "identify which one thing would help you most at this time?")	Any immediate action taken e.g. information clarified, verbal or written information given, referred to see other health care professional	Any next steps required? e.g. Referral to other services, speak to Team Leader/Manager for advice on next steps	Who is responsible for the next step or follow up?	Date of review or follow up

SECTION 5: Date of next review:..... with.....

USE OF CARER DATA

I consent to the following use of my data from this CAT form:

- ☐ anonymised information of the alerts to identify gaps in services/services development by MND Association staff
- ☐ to enable MND Association staff to act on my behalf to instigate support from other services/professionals to meet any alerts
- ☐ anonymised information of the alerts being shared with Edge Hill University team for the purposes of the pilot study to improve the CAT for future use.

Carer's Signature:..... Date:.....

Carers Alert Thermometer _ Version 2 © Edge Hill University Any correspondence to epc@edgehill.ac.uk Further information is available at www.edgehill.ac.uk/carers

Figure 1. Carers' Alert Thermometer (CAT) continued

Table 1. An overview of the online survey questions

Cohort	Question
'I registered to use the CAT...'	
For INFORMATION ONLY and I have NOT used it with any carers	Please tell us your views of the CAT and its potential for use with carers
	Is there anything you would change or refine on the CAT?
	Please tell us if you have shared the CAT or information about it with others?
	If you would like to make any other comments about the CAT or assessment of carers please share them here
For information and potential use with carers—but I have NOT used it yet	Please tell us your views of the CAT and its potential for use with carers.
	Is there anything you would change or refine on the CAT?
	Have you used other assessments with carers in the past?
	■ If Yes, please name the other assessments
	■ If Yes, please tell us how the CAT compared with other assessments, giving examples where possible
	Have you shared the CAT or information about it with others?
	Do you intend to use the CAT with carers in the future?
	■ If you would like to make any other comments about the CAT or assessment of carers please share them here
For information and potential use with carers—I HAVE used it	Approximately how many carers have you used the CAT with to date?
	What are the ages of the carer(s) you have used the CAT with?
	What is the relationship of the carer to the patient?
	How useful did you find conducting the CAT with carers? 1 (not very useful) – 10 (extremely useful)
	(If you wish to provide any comments about the usefulness of the CAT please comment in the 'other' box)
	Please tell us if there is anything you would change or refine on the CAT?
	Please share with us if using the CAT has led to any changes in your practice?
	Please tell us if you have shared the CAT or information about it with others?
	Have you used other assessments with carers in the past?
	If Yes, please tell us how the CAT compared with other assessments, giving examples where possible

CAT, Carers' Alert Thermometer

Analysis

Survey data from closed questions were analysed using IBM SPSS Statistics for Windows (Version 22; IBM Corp, Armonk, NY, USA) for descriptive statistics. Open text responses and interview data were analysed taking an evaluation approach to develop deductive codes relating to benefits, potential challenges and future directions for implementation of the CAT. Transcripts were read by two members of the research team for initial familiarisation. To ensure rigour, two members of the research team independently identified themes within the data, which were then collaboratively checked and refined to develop a final coding framework which was applied to the dataset (Braun and Clarke, 2006).

Findings

A total of 16 participants from across the two workshops responded to the survey which included AVs ($n=12$), RCDAs ($n=3$) and senior management ($n=1$). Respondents had been in their role for an average of 7.3 years (range 1–22 years). As indicated in *Table 1*, survey responses fell into three distinct cohorts. Of these, telephone interviews were conducted with 11 participants who were AVs ($n=8$), RCDAs ($n=2$) and senior management ($n=1$). Following analysis, four overarching themes were developed: i) reported use of the CAT; ii) potential benefits; iii) critical feedback; and iv) future directions. Each of these themes will be discussed in turn and illustrated using responses from the online survey and verbatim quotes from the

telephone interviews. To protect participant anonymity, identifiers are used.

i) Reported use of the CAT

In response to the survey questions outlined in Table 1, three participants reported their registration for the CAT for information purposes only, and had not used it with any carers. In contrast, seven participants had used the CAT with a total of 14 carers. Of these, six had not used another type of assessment with carers in the past. The CAT had been used by four participants with more than one carer of a partner/spouse of a person living with MND. The age of the carers ranged from 36 years to over 76 years, with the CAT most commonly being used with carers aged over 56 years ($n=10$). On a Likert scale of usefulness from 1 (not very useful) to 10 (extremely useful), participants rated 'conducting the CAT with carers' as a mean score of 7 (range 6–8).

Among survey participants who had not yet used the CAT ($n=6$), the majority had not used any other assessment with carers in the past ($n=4$). However, four stated that they would use the CAT with carers in the future, and that they had shared the CAT or related information with others ($n=4$). In contrast, two participants stated they had information on the CAT but did not indicate future plans for use, while the RCDA/management participants ($n=3$) explained that their role offered limited opportunities to use the CAT with carers.

ii) Potential benefits

Participants highlighted several perceived benefits for use of the CAT with carers of people living with MND. The first was that the CAT could provide an opportunity to not only assess the carer's existing needs, but to also map change over time. This would then allow appropriate allocation of resources according to the carer's changing needs.

I feel that it will be a useful tool used over a period of time as caring role changes with progression of the disease. (AV#6, survey)

It can be used really at any time so what I'd like to do [if] there's a new relationship with the carer, is do it before you even know much about them. Then I've got a good baseline and then review and repeat it. And you can see where those struggles are developing. (RCDA#1, interview)

An additional benefit was that the carer became the central focus during conversations while conducting the CAT. It was commented that often the carer's needs became subsidiary to those of the people living with MND. However, the CAT provided an opportunity for the focus to be on the carer and for the carer's voice to be heard.

I think one of the most valuable aspects, if you like, of the tool itself is that when you're talking to the carer, and the carer feels ... well, they are being assessed as to where they are, you know, they feel, Oh, they're actually asking me, when all the focus generally is on the person with MND. (AV#2, interview)

I feel it has great potential to frame discussions with carers, enable them to feel free to express their feelings, and agree what future support/signposting can be offered. (AV#11, survey)

Respondents also felt that the CAT provided a structure to facilitate conversations with carers, which may have been previously challenging or overlooked. As such, this was perceived to improve communication between AVs and carers and could be used to elicit more complex/in-depth information.

I think it is an excellent tool to use to engage the carer in a more detailed conversation. It is quite specific, therefore the carer can give more in-depth answers. (AV#3, survey)

I think it can sometimes be what we sometimes think is important isn't necessarily what they think is important so therefore, and like I've got the questions in front of me and I think if we can touch on those things with them then you can pick up on what is important to them. (AV#4, interview)

One interview respondent also highlighted the possibility that the CAT would be useful for providing evidence of carers' needs and experiences for other agencies, which might then be a means of exerting pressure on them to meet the carer's needs.

It was quite interesting that social services started to sit up and take notice, when we started to actually be talking about risks to carers ... So, if nothing else, if for nothing else it's a really, really useful tool for us to be able to say, 'Hang on a second here, something is happening in this family, and actually I've got some evidence to show,' because I've had that conversation with that individual only last week. (AV#6, interview)

iii) Critical feedback

When critical feedback about the CAT was requested from participants, some concerns were raised about potential changes to their role as volunteers, which might result from the use of a formal mechanism to identify carer need. In the next example, a preference for relying on the individual's experiential knowledge of supporting carers was expressed:

The process felt 'formal'. There is no scope to be able to 'assess' or 'guess' how needs are likely to develop. With our experience and knowledge of how MND

progresses, we are fairly skilled at knowing how situations develop. (AV#5, survey)

Another participant commented on the perceived formal nature of the process, but did acknowledge that given time it would probably become more informal and natural.

I found the whole process rather mechanical, which did not aid relaxation and 'opening up' by the carer. Perhaps after one has done many of these it will be more informal. I do believe that the time spent alone with a carer is very valuable. (AV#4, survey)

Some participants felt that completing the CAT to triage carer need could have the effect of increasing AV burden and workload. More specifically, a key concern was regarding the time it might take to conduct the CAT with carers.

Concerns about an additional bit of paper, or an additional load on them to input data or whatever, whether that's perceived or real. (AV#1, interview)

Concern whether as a volunteer I would have enough time to carry out CATs on all carers. (AV#9, survey respondent)

However, an alternative view was that the CAT would not increase workload but, instead, form a type of check-list, which would have the effect of alleviating AV burden.

How we have promoted this within the association is to say, 'Look, you know, use this to frame your conversations with people. Then if you have a good quality conversation with someone, actually you will have covered most of these points.' So you can use it and say at the end of that conversation 'Look we have this tool here. I just want to check I've covered all the main points,' and show it to the carer. (Manager, interview)

Strikingly, respondents felt that the people to whom they provided support did not necessarily identify as carers, and thus may be resistant to completing a 'carer' form. This is summarised in the following examples:

... and the one where the lady actually completely refused to get involved with it. That was because she said, 'I am not a carer.' (AV#7, interview)

The very word 'carer'. When you're identified as a 'carer', it alters the balance of the relationship. You're doing it for your husband, wife, whatever, because you love them, and that's, when you got married, that's what you signed up to do, and you know that they would do the same for you if they were in, if it, you know, the roles were reversed. (AV#3, interview)

iv) Future directions

Participants pointed out that there needed to be clear and realistic support for carers, following completion of the CAT, to avoid unrealistically raising expectations. As such, the support plan created during the CAT must have achievable 'next steps' which reflect what is actually available in terms of possible support for the carers. As described by participants, a 'postcode lottery' existed in some parts of England where available services may be somewhat limited.

They (AVs) were saying that they wouldn't even want to do it because it's like if you're going to highlight something and then you don't have anything to offer, that's actually even worse than not highlighting it. (RCDA#2, interview)

I mean, there are great carer support services, but they're limited so we also need to know what the restrictions are on these as well. Because we don't want to be over-promising [during the CAT]. (AV#3, interview)

However, building on this further, it was suggested that completing the CAT should encourage AVs to be more knowledgeable about available support and any restrictive criteria which might be applied before it can be accessed.

So we encourage the volunteers to create and know what the different types of support the carers can have in their areas. So it can be formal support or it could just be something really informal. So just knowing and having an understanding about services and how they work is really helpful. Because that will then feed in to the action plans on the next page of the CAT ... I mean, there are great carer support services, but they're limited, so we also need to know what the restrictions are on these as well. Because we don't want to be overpromising. (RCDA#2, interview)

An additional opportunity for the CAT was perceived to be its use as a training or induction tool for new AVs. The CAT could provide a structured framework to support and guide inexperienced AVs during their time with carers. This was even more apparent if the carer was also new to their role.

If you've got somebody new, a new patient with a new carer, with a new AV, I think it's really important that these questions are asked and perhaps this process gone through. (AV#6, interview)

That would've given me a fantastic structure and also I think when you are new, you'd be bold enough to fill in the form. (AV#1, interview)

Finally, suggestions were made by participants about the format of the CAT and inclusion of additional

KEY POINTS

- People living with motor neurone disease (MND) have varied and complex needs resulting in them requiring high levels of assistance, usually provided by family carers
- Caring for a family member with MND is known to be burdensome and to affect the carer's quality of life
- Family carers of people living with MND often neglect their own needs and wellbeing
- The Carers' Alert Thermometer (CAT) was developed as a triage tool for use by non-specialist staff, or volunteers, to identify carers in need of support
- Use of the CAT by MND Association visitors provides a structured way to engage meaningfully with family carers of people living with MND, to identify and discuss their needs.

features. For example, space for the AV to make extra notes, consideration of other carers within the home, a question for other issues, and the potential of alternative formats for the CAT, such as a prompt sheet.

Discussion

This pilot study has explored the use and usefulness of the CAT by MND Association visitors with carers of people living with MND. It has provided an opportunity for AVs and staff to report on their experiences and perceptions of the use of the CAT as a triage tool with carers of people living with MND. A key benefit noted in this study was the potential of the CAT to map change over time, particularly important given the progressive nature of MND (O'Brien and Claburn, 2016), and to allow for regular monitoring of carer wellbeing (de Wit et al, 2018a). Also, de Wit et al (2018a) refer to healthcare professionals acknowledging the importance of the caregiving role at an early stage in the disease progression. This fits with our findings where AVs recommended completion of the CAT with carers new to their role. As the CAT is a triage tool, and not a formal assessment, it can be completed with carers at an early stage and their needs monitored on a regular basis, with referral for formal carers' assessment possibly delayed until later in the disease trajectory, as advised by Aoun et al (2017).

It is widely acknowledged that the needs of family carers can be neglected (Anderson et al, 2016; Aoun et al, 2012; Galvin et al, 2018; de Wit et al, 2018a) and assistance can be required to help them to focus on their own wellbeing. The CAT provides the opportunity to shift focus, even for a short period of time, towards the carer's situation, and allows them to consider their

CPD reflective questions

- What factors do you think might contribute to the burden experienced by family carers of people living with motor neurone disease (MND)?
- How are the needs of family carers of people living with MND identified within your service?
- How might your team contribute to the wellbeing of family carers of people living with MND?

own needs. Use of the CAT helps to acknowledge the importance of the carer role and the impact of caring (de Wit et al, 2018b) by devoting time specifically to their needs. Although originally developed to be used with carers of family members with cancer or advanced progressive illness, such as MND, there is potential for alternative versions of the CAT to be developed to triage the needs of carers of family members with other conditions. A version for use with family carers of stroke survivors (CAT-S) is being piloted, while a CAT for use with young carers is being developed. Furthermore, a scoring system for identified needs has been developed and is being tested.

The reluctance of carers to acknowledge or accept the carer identity reported in this study can make it more problematic to meet their needs and reflects the wider literature (Molyneaux et al, 2011; Hughes et al, 2013); this may stem from a sense of duty to care (Anderson et al, 2016). As MND carers are often unwilling to seek help, despite the burden, there is a need for a proactive approach to supporting them (de Wit et al, 2018a). Regular use of the CAT could facilitate this. However, the use of a 'formal' carer form can be at odds with individuals' perceptions of their role as an AV who is a 'friend' to the people living with MND and their carer. This ambiguity over role boundaries has been found in previous studies of volunteer befriending roles (Lilburn et al, 2018), suggesting that it is role-related, rather than organisationally specific. This links to a concern raised in both workshops that carers may have many needs that the volunteer would be unable to meet directly or may not feel empowered to resolve. A key learning point for future implementation training and ongoing support of volunteers has been to include discussion about role boundaries and that the role of the AV is to provide information and signpost the carer to the appropriate sources of support for the identified need, rather than resolve all needs directly. This facilitative approach is supported by the next-steps advice on the back page of the CAT and additional support resource materials provided to the AVs.

Conclusion

This is the first study to investigate the use of the CAT with carers in the context of MND. This pilot study is subject to some limitations; in particular, the small sample size limits the transferability of the findings.

Only the views of MND Association visitors and staff are presented, and the findings would be enhanced by including the views of carers who had completed the CAT with AVs. A longitudinal study exploring the effectiveness of the next steps in addressing the identified alerts would provide useful evidence of the efficacy of the CAT in helping to meet the needs of carers of people living with MND. Regardless of these limitations, family carers of people living with MND are known to experience significant burden and to prioritise the needs of the people living with MND above their own. However, if their own needs are not identified and addressed, then they are at risk of carer breakdown, which may have implications for the care provided to the people living with MND. The CAT provides a structure to enable AVs to engage in a meaningful process with family carers to identify and discuss their needs. To help overcome some of the issues identified by our participants, formal instruction on the use of the CAT is now included in AV training as use of the CAT is being rolled out across the MND Association. **BJNN**

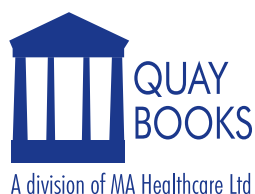
Declaration of interest: The authors declare no conflicts of interest.

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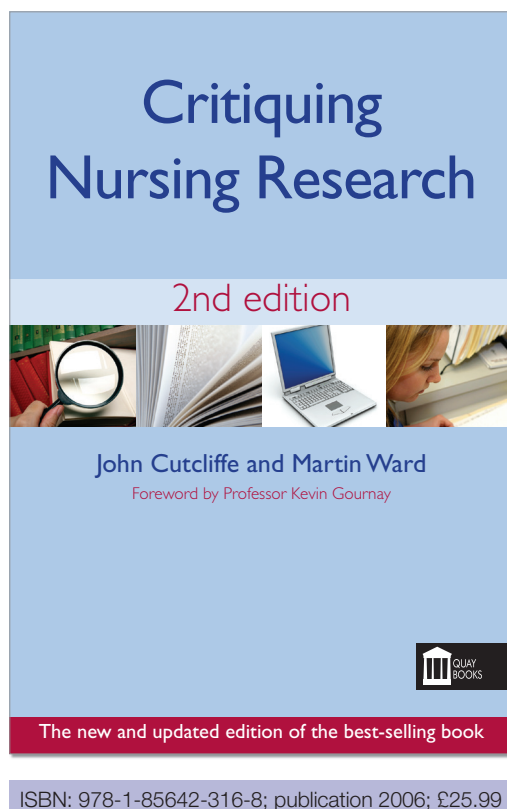
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